



Sankoh, O.; INDEPTH Network and partners, .; , COLLABORATORS; Sankoh, O.; Bangha, M.; Emina, J.B.; Herbst, A.J.; Tollman, S.; Kant, S.; Aaby, P.; Chowdhury, A.; Delaunay, V.; Diallo, A.; Khan, W.A.; Streatfield, K.; Alam, N.; Bhuiya, A.; Ha, B.T.; Molla, M.; Kebede, Y.; Alberts, M.; Toan, T.K.; Chuc, N.T.; Gyapong, M.; Jasseh, M.; Tessema, F.; Nathan, R.; Salim, A.; Masanja, H.; Punpuing, S.; Crampin, A.; Nyrienda, M.; Kouanda, S.; Mangen, F.W.; Lutalo, T.; Sewankambo, N.; Williams, T.N.; Scott, J.A.; Assefa, N.; Adama, Y.; Gebru, A.A.; Owusu-Agyei, S.; Odhiambo, F.; Otieno, W.; Sifuna, P.; Macete, E.; Urassa, M.; Larson, P.; Ezech, A.; Beguy, D.; Kyobutungi, C.; Tinto, H.; Oche, O.M.; Oduro, A.; Sie, A.; Soura, A.; Wilopo, S.; Sirima, S.; Bonfoh, B.; Juvekar, S.; Sonko, B.; Nguyen, B.P.; Meremikwu, M.; Asiki, G.; Thompson, R.; Clark, S.J.; Binka, F.; Sankoh, O.; Sankoh, O.; Herbst, A.J.; Tollman, S.; Kant, S.; Aaby, P.; Chowdhury, A.; Delaunay, V.; Diallo, A.; Khan, W.A.; Streatfield, K.; Alam, N.; Bhuiya, A.; Ha, B.T.; Molla, M.; Kebede, Y.; Alberts, M.; Toan, T.K.; Chuc, N.T.; Gyapong, M.; Jasseh, M.; Tessema, F.; Nathan, R.; Salim, A.; Masanja, H.; Punpuing, S.; Crampin, A.; Nyrienda, M.; Kouanda, S.; Mangen, F.W.; Lutalo, T.; Sewankambo, N.; Williams, T.N.; Scott, J.A.; Assefa, N.; Adama, Y.; Gebru, A.A.; Owusu-Agyei, S.; Odhiambo, F.; Otieno, W.; Sifuna, P.; Macete, E.; Urassa, M.; Larson, P.; Ezech, A.; Beguy, D.; Kyobutungi, C.; Tinto, H.; Oche, O.M.; Oduro, A.; Sie, A.; Soura, A.; Wilopo, S.; Sirima, S.; Bonfoh, B.; Juvekar, S.; Sonko, B.; Nguyen, B.P.; Meremikwu, M.; Asiki, G.; Thompson, R.; Evans, T.; Byass, P.; Adami, H.O.; Campbell, H.; Ekstrom, A.M.; Mwenesi, H.; Ross, D.; Mback, C.; Moyer, C.; Asangansi, I.; Bocquier, P.; Clark, S.J.; Gage, J.; McPake, B.; Clark, J.; Sturkenboom, M.; Weibel, D.; Bonhoeffer, J.; Dolinger, D.; Boehme, C.; Ye, Y.; Binka, F.; de Savigny, D.; Long, K.Z.; Kser, M.; Karim, A.; Musezahl, D.; Tanner, M.; de Savigny, D.; Long, K.Z.; Kser, M.; Karim, A.; Musezahl, D.; Tanner, M. (2017) [Accepted Manuscript] Why population-based data are crucial to achieving the Sustainable Development Goals. International journal of epidemiology. ISSN 0300-5771 DOI: <https://doi.org/10.1093/ije/dyx010>

Downloaded from: <http://researchonline.lshtm.ac.uk/3750306/>

DOI: [10.1093/ije/dyx010](https://doi.org/10.1093/ije/dyx010)

Usage Guidelines

Please refer to usage guidelines at <http://researchonline.lshtm.ac.uk/policies.html> or alternatively contact researchonline@lshtm.ac.uk.

Available under license: <http://creativecommons.org/licenses/by-nc-nd/2.5/>

Why population-based data are crucial to achieving the Sustainable Development Goals

Osman Sankoh and INDEPTH Network authors^[01]

INDEPTH Network, Accra, Ghana

Word count: 1838^[02]

In September 2015 the member countries of the United Nations signed up to 17 Sustainable Development Goals (SDGs). The goals contain a total of 169 specific targets which governments have committed to meeting by 2030. With their aim of eliminating poverty, protecting the planet and ensuring prosperity for all, the SDGs lay out the agenda for international development over the next 15 years.¹

Reliable data are crucial to the achievement of the goals. Without data, it will be difficult not only to know whether the world is on track to achieve its targets, but to design, implement and fine-tune the policies and programmes that will be needed. Data generation in the low- and middle-income countries (LMICs) that are the primary focus of the goals has been notoriously uneven (for example, in the areas of climate data,² education,³ economic data⁴ and poverty and census data⁵). Many poorer countries lack the requisite human and financial resources to gather robust and accurate data. Others lack the will, failing to realise the benefits of evidence-based policy-making. In others, data (for example census or poverty data) are manipulated for political purposes. Many international donors, too, have neglected data collection, funding for which amounted to just 0.16% of all aid in 2011.⁵ They often rely instead on estimates, but although the latter are interesting at a global level, empirical data are required at country level and for tracking sub-national trends.

A notable exception to this general rule are the empirical data collected in 20 LMICs by the 49 health and demographic surveillance systems (HDSSs) that make up the INDEPTH Network (www.indepth-network.org). These HDSSs have amassed a vast array of longitudinal health,

socio-economic and demographic data on hard to reach rural and urban communities covering periods of many years. The HDSS sites monitor births and deaths, observe population changes through fertility rates, mortality rates and migration, track changes in household wealth, and trace the evolution of health threats and other social determinants of health. Bringing together the cream of international health and demography scientists from LMICs and high-income countries, HDSS researchers also conduct studies in their communities to assess the impact of health systems, health policies and interventions.⁶

The HDSS sites in the INDEPTH Network currently observe the life events of over 3.8 million individuals in Africa, Asia and Oceania. Their data, which are made publicly available through the INDEPTH open data platform,⁷ are collected through regular visits to every household in a geographically-defined area. They will be important for assessing progress towards a number of the SDGs, and in particular the third goal - to 'ensure healthy lives and promote well-being for all at all ages.' This goal contains nine targets, and INDEPTH and its members already produce robust, detailed data on each of them.

Here we briefly present INDEPTH's work on each of the targets. The first two targets aim to reduce the global maternal mortality ratio and to end preventable deaths of newborns and children under 5 years of age. All INDEPTH member centres track pregnancies, newborn births and deaths, and infant and child morbidity and mortality on a longitudinal basis. ~~Chakaria HDSS in Bangladesh, for example, has~~ Many sites have already begun to measure progress towards the SDGs and publish the data collected. ~~Chakaria HDSS in Bangladesh, for example, in 2015, it~~ found a neonatal mortality rate in its surveillance area — a rural community in Bangladesh — of 34.1 per 1,000 live births, higher than the national rate of 28 and than the 2014 rate of 31.5 per 1,000. It found that infant mortality was 44.4 per 1,000 live births, compared with a national rate of 38, and that under-5 mortality was 58.9 per 1,000 (the national rate was 46 per 1,000). The centre also tracks the proportion of births that take place in health facilities (23.4% in 2015), and

that are assisted by a skilled birth attendant (35.3%).⁸ A number of centres have also tested health interventions in these areas, such as Vitamin A supplementation⁹ and micronutrient supplementation for anaemia.¹⁰ INDEPTH's Working Group on Maternal and Newborn Health, moreover, brings together scientists from across the network to study maternal, newborn, infant and child health epidemiology and the impact on it of health interventions.

The third health target is to end the epidemics of AIDS, tuberculosis, malaria and other neglected tropical diseases and to combat other communicable diseases. INDEPTH members in Africa and Asia have conducted hundreds of studies of morbidity and mortality from communicable diseases, and have tested a wide range of interventions to control them. The Africa Health Research Institute in South Africa showed how antiretroviral therapy for HIV/AIDS increased adult life expectancy by 11.3 years in a rural South African community, and that the benefits far outweighed the costs of providing treatment.¹¹ Several INDEPTH sites contribute to the Analysis Longitudinal Population-based HIV/AIDS data on Africa (ALPHA) network which contributes detailed statistical estimates of HIV incidence, mortality patterns and fertility impacts to the [UNAIDS Reference Group on Estimates, Modelling and Projections](#), which oversees the data and methods used for producing HIV epidemic updates and projections in African countries. A study examining the rate of infection with *M.tuberculosis* in children under 5 years of age in the Karonga DHSS showed that the majority of infected children had acquired the infection through casual contact or undiagnosed cases^[03]. A study by the Navrongo HDSS in Ghana which found that bed nets soaked in permethrine reduced child deaths by 17 per cent led to the adoption of bed net provision into health policies across Africa.¹² The Manhiça Health and Demographic Surveillance System site in Mozambique developed a nationwide malaria risk map for the National Malaria Control Programme, and conducted drug trials which persuaded the national government to replace chloroquine with amodiaquine and sulphadoxine-pyrimethamine as its principal malaria treatment.¹³ The oral

cholera vaccine tested by Matlab HDSS in Bangladesh, meanwhile, is now recommended by the World Health Organisation.¹⁴

The fourth target is to reduce premature mortality from non-communicable diseases (NCDs) and to promote mental health. INDEPTH member centres' verbal autopsy data tracks mortality from NCDs and other diseases. For example, a multi-site study of more than 80,000 deaths over fifteen years in African and Asian demographic surveillance areas found that NCDs accounted for 36% of deaths.¹⁵ The Network's working group on Adult Health and Aging monitors the evolution of NCDs and their risk factors at HDSS sites in South Africa, Tanzania and Ghana as Africa goes through the health transition. INDEPTH member centres in five countries, moreover, collaborated on the largest study to date of epilepsy in Africa, which found significantly higher rates of epilepsy among adults who had suffered parasitic diseases, and among those who as infants had had complications during birth.¹⁶ To examine the rise in obesity and associated NCDs in Africa, INDEPTH has embarked on a study to identify genomic and environmental contributions to cardiometabolic diseases in Africans.¹⁷ This six-site population cross-sectional study in Burkina Faso, Ghana, Kenya and South Africa, including approximately 12,000 adults mainly between the ages of 40 and 60 years, will provide baseline data on the prevalence of obesity, hypertension, diabetes and chronic kidney diseases and risk factors for non-communicable diseases. The participants will be tracked for mortality and progression to NCD status.

Data on targets five and six — preventing and treating substance abuse, and halving deaths and injuries from road traffic accidents — is hard to come by in many LMICs. INDEPTH sites' verbal autopsy data, which monitor morbidity and mortality from road traffic accidents as well as from diseases caused by substance abuse, are a rare and important exception, and are helping to improve burden of disease data across Africa and Asia.¹⁸ In addition, INDEPTH is developing a five-year research project on adolescent health, including intervention studies assessing how to

reduce addictive behaviours through marketing campaigns, conditional cash transfers and training of health workers.

The seventh target — ensuring universal access to sexual and reproductive health-care services — has been a focus of HDSS sites for decades. INDEPTH is an LMIC institutional partner on the Population Council's EVIDENCE project, which seeks to use evidence strategically to expand access to family planning and reproductive health services worldwide. INDEPTH's working group on Fertility and Family Planning is leveraging existing fertility data from HDSSs to produce a set of comparative studies across the network. It also plans to use longitudinal demographic data to understand and quantify the fertility transition in the poorest countries, and to conduct impact evaluations to discover which policies and interventions are most effective.

Finally, the eighth target aims to achieve universal health coverage (UHC) and access to quality services, medicines and vaccines, while the ninth aims to reduce mortality and morbidity from environmental pollution and contamination. INDEPTH and its members collect data and test interventions in both areas. For example, an INDEPTH project on UHC developed a tool for use by HDSSs to capture information on need, access to health care and utilisation patterns of health care at the district level. The INDEPTH Effectiveness and Safety Studies of Antimalarials in Africa have brought together African researchers to conduct effectiveness studies of three anti-malarial drugs among 30,000 individuals, producing the largest available database on anti-malarial drug impact. Over the next five years, moreover, INDEPTH, using its new Comprehensive Health and Epidemiological Surveillance System (CHESS),¹⁹ will take a leading role in safety surveillance of medicines, vaccines, biological products and other medical interventions in LMICs. With regard to environmental pollution, INDEPTH's working group on Environment and Health is using longitudinal data from multiple HDSS sites to monitor the impacts of environmental changes on health and migration, as well as testing interventions to strengthen climate change mitigation and adaptation in sub-Saharan Africa.

The INDEPTH platform, then, which is often the only source of community-level health data in the countries where its members operate, is uniquely placed to assist LMICs to track progress against and hasten the achievement of the Sustainable Development Goals. HDSS sites' longitudinal tracking of births, migrations and deaths, morbidities as well as studies to test interventions are important to the SDGs relating to areas such as eliminating poverty, ending hunger and promoting gender equality, and they are vital to the health SDG.

INDEPTH is working to strengthen its contribution to measuring and achieving the SDGs. Like other organisation such as UNICEF and DHS, the Network plans to map each SDG to develop and publish baseline metrics so that progress across its current 20 LMICs can be assessed. It will publish regular updates of progress towards the health and other SDGs, and work with local and national officials to integrate the data to improve their own monitoring efforts, and to use it to design effective, evidence-based policies and programmes. Most countries that host INDEPTH HDSS sites lack Civil Registration and Vital Statistics (CRVS) systems, for example. Where such systems are in place, they register only a small proportion of births and deaths. As major international donors have become interested in CRVS, INDEPTH has developed links with health systems to improve their collection of such data, both assisting with capacity strengthening and making its own data available as a comparative tool for monitoring CRVS effectiveness.

Finally, the last of the SDGs pledges to promote capacity development for implementing the goals and to 'increase significantly the availability of high-quality, timely and reliable data disaggregated by income, gender, age, race, ethnicity, migratory status, disability, geographic location and other characteristics relevant in national contexts.' Through its own longstanding programmes to build the capacity of LMIC health, biomedical and demographic researchers, INDEPTH has helped create several generations of demographic and epidemiological expertise that will be of central importance for attaining as well as monitoring the SDGs.

References

1. United Nations. Sustainable Development Goals. United Nations website. 2016. Available at: <http://www.un.org/sustainabledevelopment/sustainable-development-goals/#>. Accessed 1 December 2016.
2. UK Department for International Development. Climate proofing Africa. London: DFID, 2005.
3. Bloom DE. Measuring global educational progress. Cambridge, MA: American Academy of Arts and Sciences, 2006.
4. Weston M. The Big Squeeze: Nigeria on the Brink. In E O'Brien, D Steven (eds): The new politics of strategic resources. Washington DC: Brookings Institution, 2014.
5. Melamed C. Development data: how accurate are the figures? *Guardian* 2014; 31 January.
6. INDEPTH Network website: <http://www.indepth-network.org/about-us>. Accessed 1 December 2016.
7. Sankoh O, Herbst AJ, Juvekar S, Tollman S, Byass P and Tanner M. 'INDEPTH launches a data repository and INDEPTHStats.' *The Lancet Global Health* 2013. doi:10.1016/S2214-109X(13)70034-2.
8. Hanifi SMA, Sultana A, Mia MN *et al*. Chakaria Health and Demographic Surveillance System Report – 2015: focusing on the Sustainable Development Goals. Scientific Report No. 134. Health Systems and Population Studies Division, ICDDR, B. Dhaka. November 2016.
9. Ghana Vitamin A Supplementation Trials (VAST) Study Team. Vitamin A supplementation in northern Ghana: effects on clinical attendance, hospital admissions, and child mortality. *Lancet* 1993; 342: 7-12.
10. Hirve S, Bhav S, Bavdekar A *et al*. Low dose 'Sprinkles' – an innovative approach to treat iron deficiency anemia in infants and young children. *Indian Pediatrics* 2013; 44(2): 91-100.
11. Bor J, Herbst AJ, Newell ML, Bärnighausen T. Increases in adult life expectancy in rural South Africa: valuing the scale-up of HIV treatment. *Science* 2013; 339(6122), 961-965.
12. Binka FN, Adazu FK, Adjuik M *et al*. Impact of permethrin-impregnated bed nets on child mortality in the KasenaNankana district, Ghana: a randomized controlled trial. *Trop Med Int Health* 1996; 1: 147-54.
13. Abacassamo F, Enosse S, Aponte JJ *et al*. Efficacy of chloroquine, amodiaquine, sulphadoxine-pyrimethamine and combination therapy with artesunate in Mozambican children with non-complicated malaria. *Trop Med Int Health* 2004 Feb;9(2):200-8.
14. Clemens JD, Sack DA, Harris JR *et al*. Field trial of oral cholera vaccines in Bangladesh: results from three-year follow-up. *Lancet*. 1990 Feb 3; 335(8684):270-3.
15. Streatfield PK, Khan WA, Bhuiya A *et al*. Adult non-communicable disease mortality in Africa and Asia: evidence from INDEPTH Health and Demographic Surveillance System sites. *Global Health Action*. 2014 Oct 29;7:25365. doi: 10.3402/gha.v7.25365.
16. Ngugi A, Bottomley C, Kleinschmidt I *et al*. Prevalence of active convulsive epilepsy in sub-Saharan Africa and associated risk factors: cross-sectional and case-control studies. *Lancet Neurol*. 2013 12(3): 253–263.
17. Ramsay M, Crowther N, Tambo E *et al*: H3Africa AWI-Gen Collaborative Centre: a resource to study the interplay between genomic and environmental risk factors for cardiometabolic diseases in four sub-Saharan African countries. *Global Health, Epidemiology and Genomics* 2016; 1, e20, page 1 of 13. doi:10.1017/ghg.2016.17.
18. Streatfield PK, Khan WA, Bhuiya A *et al*. Mortality from external causes in Africa and Asia: evidence from INDEPTH Health and Demographic Surveillance System Sites. *Global Health Action*. 2014 Oct 29;7:25366. doi: 10.3402/gha.v7.25366.
19. Sankoh O, INDEPTH Network. CHESS: an innovative concept for a new generation of population surveillance. *The Lancet Global Health* 2015. [http://dx.doi.org/10.1016/S2214-109X\(15\)00180-1](http://dx.doi.org/10.1016/S2214-109X(15)00180-1)